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ABSTRACT

This paper identifies three different historical perspectives about citizens with developmental disabilities and their relationships to their fellow citizens and to state and federal governments. These perspectives are compared and contrasted as a basis for thinking about the future. A chart illustrates the perspectives of a distant past, a more recent past, and the present. For example, the perspective on individuals with disabilities has moved from a person possessed, to a person as a mechanism, to a person of the whole. Intervention efforts have moved from a hopelessness to intervene, to rehabilitating the person, to a dual focus on the person and the environment. The dominant political, legal, and economic values of America--liberty, equality, and community--are discussed, and the problems with individualistic utilitarianism when applied to individuals with disabilities are outlined. The paper proposes thinking about people's lives in a "communitarian" way, focusing on the interdependence of people and their duties to a common good. The roles of policymakers in the field of developmental disabilities in addressing the issues of interdependency are discussed, with recommendations in 13 categories including: generic agencies' roles, informal support, family-focused action, supported employment, financial sustenance, special education, quality assurances, self-advocacy, monitoring and protection, governmental structure, courts and judicial administration, research, and prevention. (19 references) (JDD)

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The Communitarian Perspective

Thoughts on the Future for People with Developmental Disabilities

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The Communitarian Perspective

Thoughts on the Future for People with Developmental Disabilities

PO-3

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to

North Carolina Developmental Disabilities
Planning Council

October 1991

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The University of Kansas, 1991

ACKNOWLEDGEMENTS

It is a pleasure to return to North Carolina and to work again with the Developmental Disabilities Planning Council. I served as special counsel to your predecessors for several years and most memorably when, under Sen. Ralph Scott's leadership, they sponsored and secured the passage of North Carolina's limited guardianship legislation in 1978, over the opposition of many entrenched constituencies, especially the clerks of court.

It also is an honor to be asked to speak about the future of the lives of citizens with developmental disabilities and the nature of services to them. You may know that I developed my career in disability law when I was professor of public law and government at the Institute of Government at the University of North Carolina in Chapel Hill, beginning in the early 1970s. My interest was piqued not just by my son, who has two developmental disabilities, but also by a visit I made at the Governor's request to Western Carolina Center as part of a team sent to inquire about and monitor the use of aversive interventions at that Center. I learned a great deal from that and subsequent visits to the Center.

OVERVIEW

You have asked me today to address the future and give you advice about what you might do to influence it. I cannot do that without looking at the past and the present.

If we do that together, we will find three different historical perspectives about citizens with developmental disabilities and their relationships to their fellow citizens and to state and federal governments. I wish to compare and contrast these perspectives so we will have a basis for thinking about the future. (I will not, however, provide references and citations for this section.) I then will comment on a different way of thinking about our

present. Finally, I will focus on the future.

In a nutshell, I will argue that we need to stop thinking about the lives of people with disabilities and our own lives in only the traditional liberal way. That way emphasizes the importance of liberty, autonomy, and individualism and has been necessary but not sufficient for people with disabilities and ourselves and will not be particularly helpful to them and us in the future, if we think only in that mode. I will suggest we need to think in a different way, which many people now call "communitarian." Contrasted to the "liberty-autonomy-individualism" way of thinking, which focuses on independence of people and their rights, the "communitarian" way of thinking focuses on the interdependence of people and their duties to a common good. If you recognize that our country has chosen to live by three principles -- liberty, equality, and community -- you will understand that I want us to think about the third principle and its utility for the future.

Now, let me lay the foundation for this shift in thinking. I will do so by looking at the distant past, the more recent past, and the present as they affect the lives of citizens with developmental disabilities.

THE DISTANT PAST, MORE RECENT PAST, AND PRESENT

Table 1 is a chart that rather simplistically illustrates the perspectives of a distant past, a more recent past, and the present. Because it is a summary and meant only to launch your consideration of the future, it is necessarily less than fully and perfectly comprehensive or accurate. It is, nonetheless, a fair and defensible portrait of views of people with developmental disabilities.

DISTANT PAST	MORE RECENT PAST	PRESENT
possessed	mechanistic	holistic
witholding justified presumed	withholding debated	treatment
medical model	developmental model	holistic
nontreatment intervention	behavioral treatment	bio-behavioral
hopeless to intervene	rehabilitate person	dual focus on person and enviornment
inherent disability	potential to learn, earn	social construct
focus on person	focus on family and person	three-way focus on person, family, & community
parentectomy	adoption, foster care	family preservation
unable:disability	productivity	contribution
dependence	independence	interdependence
segregation	integration	inclusion
no services	specialized services	generic services with adaptations
charity	rights	rights and compassion
no rights	rights	more rights
second class citizen	more equal citizenship	full citizenship
competitive model with liberty as value	liberty plus equality	liberty, equality community
unnequal treatment	equal treatment	unequal but not invidious treatment
total deprivation of autonomy	partial deprivation	protection and advocacy
no rights	negative rights	positive rights

The distant past: the individual was viewed as a changeling, possessed

of a devil, one who represents a living punishment to others (parents). The more recent past: the person became an object of scientific interest and research and a target for the application of the scientific method, an organism who can be understood and "corrected" by the means of a mechanistic, scientific, reductionistic, modern paradigm. The current perspective: the person is a "whole person" who must be understood, and whose life must be taken into account, on a holistic basis, where behavior, physiology, genetics, environment, communication, nurture, and other factors are just part and parcel of the whole. The perspective moves from a person possessed, to a person as a mechanism, to a person of the whole.

The distant past: a person who cannot benefit from medical or other specialized care, who is not "curable", and whose abandonment, even death, is not unwarranted. The more recent past: a person who can benefit, but only to a degree. Not every person with a developmental disability is "improvable" and thus some selective nontreatment, some selective "letting die," is warranted. The present: a person who can benefit from specialized care and for whom nontreatment is warranted only if it will be futile, too painful to be humane, or experimental and without promise of benefit for the person. Thus, the perspective moves from one of that presumes it is justified to withhold care to one that presumes it is not.

The distant past: a person whose disability is essentially medical and able to be addressed best by physicians. The more recent past: a person whose disability is essentially developmental and should be addressed by an interdisciplinary team consisting of physicians, educators, psychologists, speech-language-hearing specialists, etc. The present: a person whose disability requires a holistic view -- where the professional disciplines and family, friends, and community are all involved in amelioration and

habilitation. The perspective moves from a medical model to a developmental model to a holistic model.

The distant past: a person whose behavior is beyond our understanding and ability to change. The more distant past: a person whose behavior is "learned" and correctable, even by aversive means; a person who is no more than the sum of acquired behaviors, all of which can be extinguished, even if only by punishing means. The present: a person whose behavior is indeed learned but whose behavior also is the result of presently poorly understood or totally incomprehensible biological or bio-behavioral conditions and whose behavior is a manifestation not only of what is "learned" but of choices and preferences. Thus, the perspective moves from nontreatment, to treatment based on behaviorism alone, to treatment that recognizes that behavior results from complex and poorly understood factors.

The distant past: a person whose life, even quality of life, is relatively hopeless and who should be abandoned, even if the abandonment means the termination of life itself. The more recent past: a person whose rehabilitation is possible if specialists bring their vast talents to bear and the public commits huge amounts of resources to the tasks of rehabilitation. The present: a person whose disability can be overcome by specialized interventions and also by accommodations by the society in which he/she lives. Thus, the perspective moves from abandonment and hopelessness, to one of hope by rehabilitation, to one of "dual accommodations": The person is "improved" by rehabilitation or other interventions (such as special education) as well as by our accommodations (as required by the nondiscrimination laws).

The distant past: a person who has such an inherent disability and difference that no interventions are warranted. The more recent past, a person who can be "improved" (rehabilitated, educated, or "cured"). The

present: a person whose disability is converted into a "handicap" by the failure of the world to accommodate to the difference that the disability makes. Thus the perspective moves from inherent disability, to rehabilitation and education potential, to the "social construct" perspective. The distant past: a person whose help is system based and who must fit into a system of services for people like him/her (specialized system that requires the person to fit in order to benefit). The more recent past: a person to whom the human service system must accommodate, who alone is the focus of interventions. The present: a person who, with the family and friends and community, must be accommodated by a system of services. Thus, the perspective moves from being system-centered, to person-centered, to family-friend-community centered.

The distant past: a person who is the sole focus of planned interventions, the only justifiable object of society's concern, interest, study, research, intervention, and financial aid. The more distant past: a person whose life as a family member requires that interventions should encompass not just the person but also the family. The present: a person whose life is best understood, and therefore most amenable to change, in the context of the self, the family, and society as a whole. Thus, the perspective moves from person, to person and family, to person and family and community.

The distant past: a person who necessarily will be a burden to family, friends, community, and therefore should be separated from them, by institutionalization, for their sake and for his/her own. The more recent past: a person who may be burdensome and for whom an institution always must exist -- a place for the "residual" population within this total populations -- or for whom foster care, specialized adoption, and even family support (by

special subsidies to the family) is necessary and appropriate. The present: a person who is entitled to live in the family because the family is a better place for growth and are than any state system such as adoption or institutions, whose family and friends benefit from his/her presence, and who, with the family and friends, are entitled to special family preservation efforts. Thus, the perspective moves from "parentectomy" to "adoption/foster care" to "family preservation."

The distant past: unable to learn or earn. More recently, able to learn and earn and be productive. Currently, persons who, while not always able to be economically productive, still make contributions. The perspective moves from a person who is unable, to one who can be productive, to one who can contribute, if not in an economic way.

The distant past: a person who will always be dependent on others and therefore subject to the parens patriae doctrine, even if its exercise (which is supposed to protect) causes harm. The more recent past: a person who is capable of independence, sometimes without support but almost always with support. The present: a person who is interdependent with us, just as we are with him/her and with each other. Thus, the perspective moves from dependence, to independence, to interdependence.

The distant past: A person who should be segregated because the difference is so great, kept separate and apart. The more recent past: a person who may not be segregated but whose full integration or full inclusion is not warranted. The present: a person who can, with accommodations, be integrated and included in the lives and life activities of people without disabilities. Thus, the perspective moves from segregation, to integration, to inclusion.

A person whose disability is so great as a matter of course that it is

justified not to educate or rehabilitate him/her; a person who cannot earn or learn. The more recent past: a person who can learn and earn, but only with specialized interventions, delivered by specialized personnel, and only in specialized settings. The present: a person who not only can learn but also can benefit from learning, earning, living, and recreating in settings and among individuals who do not have specialized or separate lives. Thus the perspective moves from no services, to specialized services and settings, to generic services and settings, with accommodations and adaptations (such as the 'REI/school restructuring/ADA-compliance/integration/inclusion efforts)..

The distant past: a person who is aided best by charity, whom it is the privilege of others to help. The more recent past: a person who has constitutional and even natural rights. The present: a person whose needs need to go beyond benevolence, beyond rights. Thus, the perspective moves from charity, to rights, to something beyond, but not in exclusion of, rights.

The distant past: a person who is entitled to no legal rights or standing, but only, at best, the benefits (and detriments) of the parens patriae doctrine. The more recent past: a person who has limited legal rights and standing. The present: a person who, so long as reasonable accommodations are possible, is entitled to the same rights as others to participate in America's mainstream. Thus, the perspective moves from no rights, to some rights, to greater rights.

The distant past: a person who necessarily will be a second-class citizen, because of the disability, and therefore without status, rights, and roles similar to those without disabilities. The more recent past: a person who has limited roles, such as living outside of institutions but in group homes or other protected and separate settings, or such as working in a sheltered workshop or other protected environments. The present: a person

who can, with support, be employed in competitive settings. Thus, the perspective moves from one who has second class status to somewhat less than second class status but not yet full status.

The distant past: a person who cannot survive in the Lockean, individualistic, utilitarian, competitive world of capitalism within a democracy (an individual-supremacy model). The more recent past: a person who can survive in that kind of world, with support and protection, and who must do so, for that kind of world should not be altered. The present: a person whose life is so linked with others, whose lives themselves are so interdependent, that "liberty" should no longer be the dominant value (for him/her and for any other American) Thus, the perspective moves from the competitive model, with its Social Darwinian precepts and consequences, to the liberty-plus-equality perspective, where the person with a disability is "free/liberty" to compete and will be trained/rehabilitated/educated to do so (see America 2000 initiative of the Bush Administration), but who also is "equal/equalized" by the provision of negative and positive rights.

The distant past: a person who, because of the disability, is and should be a second-class citizen, who does not deserve equal standing or equal opportunity relative to nondisabled people. The more recent past: a person who is entitled to the equal protection of the laws, but nothing more -- to a level playing field. The present: a person who is entitled to a special understanding and application of the idea of equality, to accommodate for the disability. Thus, the perspective moves from unequal, to exactly equal, to equal plus accommodation or even unequal but nonharmful/discriminatory treatment.

The distant past: a person whose disability renders him or her totally incompetent, and therefore subject to plenary disability and guardianship.

The more recent past: a person who has situational capacity, with abilities that depend on certain situations and roles, and therefore not subject to plenary guardianship but entitled, at most, to limited guardianship. The present: a person whose autonomy is threatened by guardianship of any kind and who is entitled to protection and advocacy instead of the deprivation of rights and the transfer of rights to another. The perspective is one that moves from total deprivation, to partial deprivation, to protection and advocacy against deprivation of autonomy.

The distant past: a person who, if helped at all, is aided by concerned members of society, who act without having the legal obligation to do so. The more recent past: a person who has legal rights and can impose duties on others, by exercising those rights. The present: a person who has not only rights against the harmful behavior of others, so-called negative rights, but also rights to certain levels of public support, so-called 'positive rights'. Thus, the perspective moves from no rights, to negative rights, to 'rights' to and entitlements to certain levels of life-supporting and live-enhancing services, publicly funded.

A LITTLE LESS CONCERN WITH LIBERTY

This far too simplistic perspective serves only to provide a launching pad to discuss the future for people with developmental disabilities. I wish to address the issue of the future by referring to our country's dominant traditions, their utility for the future as they are now practiced, and their impact on people with developmental disabilities. I then will make specific suggestions for your consideration.

The dominant political, legal, and economic values of America are <u>liberty, equality, and community</u>. Over our history, the most persuasive and pervading of these three has been liberty.

Born of our rebellion against Great Britain, encapsulated into our Constitution, nurtured by the seemingly endless frontier of the west, protected by our location between two great oceans, and consolidated by our adoption of capitalism, the liberty principle is appealing on many dimensions and put into play in many areas of our national life.

We celebrate "rugged individualism," an ideology so persuasive that even today television and the movies evoke the mythical Sir Lancelot as an advertising or script hero. As Robert Bellah and his colleagues have so persuasively shown in Habits of the Heart and more recently in The Good Society, we adhere to the liberty principle because we believe that it is the principle most likely to nurture our pursuit of property, whereby we achieve happiness. At the individual level, we have come to believe that our success, and thus our property and wealth, depends on our ability to negotiate competently a series of requirements, whether in school or the workplace. These are, in a word, the abilities of technical expertise and interpersonal skills (The Good Society, p. 42). Our educational system adheres to this belief and dovetails into our worklife (id. p. 43). Thus life becomes a competitive race to acquire certain objective markers of success: good grades result in good jobs, which in turn allow us to acquire houses, cars, appliances, vacations, retirement, and insurance against the pitfalls of bad health, disability, and even our death (id. p. 43). In short, as Bellah and his colleagues argue, we have interpreted the principle of liberty as a principle of utilitarian individualism -- the belief that the greatest good will obtain for the greatest number when each of us competes forcefully and fairly against each other for admission to independent schools or governors' academies, elite state or private universities, leadership and remuneration in the workplace, certain neighborhoods, and retirement communities.

Several other contemporary scholars sound similar themes and concerns. In Rights Talk: The Impoverishment of Political Discourse, Mary Ann Glendon traces the development of the law's concerns with the rights of individuals and shows how Americans' predisposition to frame all issues into a context of "my rights vs. your rights" causes division and impedes development of a common dialogue and focus. "Rights talk" is predicated on the concept of the autonomous individual, the person who is the "solo rights bearer". By that term, Glendon means a person who alone has claims to rights against others, a person who, because personal autonomy is the principal value in American legal and economic history, stands alone as a claimant of rights that are acquired only by diminishing the claims or rights of others (Glendon, pp. 40, 45, 48, 57, 67, 107).

In this posture, the solo rights bearer, and all others like him/her, has caused untoward and unwelcome consequences. These include interference with working for the common good (id., p. 14-15, 171) and disadvantaging those who already are at risk or marginalized, such as those who are ill, disabled, elderly, or poor (id., p. 71, 90, 101-2, 105, 154). In addition, the solo rights bearer, and others similarly motivated, obscures discussions of responsibility, community interests, and concern for others (id., p. 74, 77, 90, 101-2, and 171-3); creates a situation in families in which the members assert rights against each other, thus causing or contributing to the decomposition of the family (id., p. 57 and 67); disdains interdependence and sees reliance on others as a weakness (id., p. 73 and 173); and ignores the fact that all of us are indeed interdependent (id., p. 74 and 171-3). Finally, the solo rights bearer diverts us from looking after and participating in the mediating structures and institutions of society, such as religious, civic, political, and special-interest groups, in which we can work

out the balances between individual rights on the one hand and community or common rights on the other (id., p. 75 and 107). As are Bellah and his colleagues, Glendon is concerned about the common good; her analysis begins at a different point than Bellah et al.'s but draws similar conclusions: there may be too many rights and there certainly is too great a focus on rights-acquisition, with the consequence that Americans are too little concerned about responsibility, community, and the common good.

In a still different way, Martha Minnow, who like Glendon also is a lawyer, draws our attention to the unwelcome consequences of the rights focus. In Making All the Difference, Minnow argues that the law's focus on creating rights for individuals, especially rights of one family member against another or against the family as a whole, has brought us to an unsatisfactory pass. Rather than creating nurturing and supporting families, the rights focus has prevented us from seeing how rights and relationships can both be advanced simultaneously, that is, how rights of individuals and their common concerns for others and others' lives, can be assisted and made mutually compatible rather than mutually exclusive. The case of Phillip Becker, a pre-teen with Down Syndrome whose parents objected to heart surgery for him, posed most clearly the rights focus: if a court orders Phillip's surgery, on the ground that his right to live longer and stronger is important to preserve, then the court necessarily diminishes his parents' rights to control his upbringing, and on the other hand if the court sustains his parents' objections to surgery, it unavoidably shortens his life expectancy. Cases involving the rights of minors to abortions, without having to seek parental consent, likewise pose a rights vs. rights dilemma: to grant the minor the right to an abortion absent parental consent advances her rights of autonomy but reduces theirs, while to deny her rights to an abortion unless she obtains her

parents' consent reduces her rights but increases theirs and their control over her. For Minnow, neither of the results is acceptable. When one person can "win" only at the expense of another, the common interests of all parties is obscured and a win-lose, rather than win-win, dichotomy is created. The way out of this dilemma, she argues, is to focus less on the rights of the individuals against each other and more on the ways in which the parties within the relationship can be brought to find a common ground and mutual accommodations. Thus, like Bellah et al. and Glendon, Minnow urges us to <u>focus more on relationships, common goods, responsibilities, and accommodations than on individualistic and exclusionary rights-assertions</u>.

Neither Bellah et al., Glendon, nor Minnow argue that rights-focusing has been all bad or even that hard-won rights, whether possessed by mainstream or minority Americans, should be repealed or reduced. There are, after all, many advantages to a rights focus and to the assertion of rights of individuals against the state, against a majority or minority, and against each other. America is immensely wealthy, egalitarian, free, and renewable, all because Americans have believed in the blessings of liberty and put those beliefs and blessings to work for themselves individually and collectively. Yet, paradoxically, the very liberty that we value and apply has had some untoward results, results that are particularly unsettling in this last decade of the century.

Arguably, the disintegration of the nuclear family is caused in part by the fact that Americans give individual fulfillment, even within the family, higher priority than the responsibilities of family members to each other (Bellah, et al., id. p. 46). Glendon (id., p. 57) and Minnow (id., pp. 269-277, 341-350) make similar arguments. Careers count more than kids; success counts more than spouses. Individually and collectively we evaluate our lives

in terms of economic advances and standing, and we evaluate our self-worth by measuring our financial status (Bellah, et al., id. p. 58). Yet we seem to be reaching out for something more than work and jobs to fulfill us; causes abound, and volunteerism calls us to causes that enrich our lives.

Consistent with the view that liberty is the predominant value and entails the pursuit of property and thus happiness, we came to see our government as having duties to our economy. John Locke and his followers (Hobbes, Bentham, Hamilton, et al.) argued that the role of government is to provide a minimum of order so that individuals can acquire property (id. p. 67, 83). That explains in large part the creation of the corporation and indeed our law and political economy. The corporation is a legal fiction whose purpose is to maximize individual profit and reduce individual risk; the law's role, during the 19th and even well into the 20th century, was to immunize the corporation from collective responsibility other than to its shareholders. Another fiction of the law, maintained well into this century and only now beginning to wither, was that individuals are free to enter into contracts with each other; they are in a natural state of being individually "free" and therefore "equal." Their contacts, even those that resulted from the most disparate bargaining positions and within the most unequal power relationships, were sacrosanct and not to be disturbed (id. ch. 3, passim; see also Minnow). The rugged pursuit of self interest, through corporations and contract and property law, taught a lesson that every Horatio Alger proved and that no poor or unsuccessful person, especially no person with a disability, disproved:

"Our individualistic heritage taught us that there is no such

thing as the common good but only the sum of individual good. But in our complex, interdependent world, the sum of individual goods, organized only under the tyranny of the market, often produces a common bad that eventually erodes our personal satisfactions as well." (id., p. 95).

Not unexpectedly, Glendon and especially Minnow concur that our economic heritage, derived from Locke, Mills, and the Hamiltonians, has been institutionalized into our laws of corporations, contracts, and property, with the similarly inevitable and unwelcome consequence that the rights, claims, needs, and preferences of the individual have obscured those of the community as a whole.

That may be one reason why we feel so dissatisfied with respect to our national institutions such as families, schools, churches and synagogues, political parties, and governments. Somehow we have come to believe that they have not fulfilled us even as we asked them to fulfill us by allowing us to pursue property.

Admittedly, Bellah and his colleagues do not apply their argument to individuals with disabilities. Glendon does not either except with respect to already disadvantaged and marginalized individuals (who presumably include those with disabilities) (id., p. 74, 90, 101-2, 105, and 154). Only Minnow is explicitly concerned with the rights of individuals with disabilities, and her treatment of the special education, right to treatment, and right to life issues is powerful and persuasive of her argument that the rights focus has been less than satisfactory for them and for the rest of us as well. That, however, is precisely what I want to do now.

<u>When applied to individuals with disabilities, individualistic utilitarianism is particularly problematic</u>. (I refer, below, to implications

of this perspective and to the recommendaitons I make, beginning at page 36.) It teaches us that we should look out just for "number one" and that the "bottom line" is our individual balance sheet. Instead of an unselfish concern for others -- whether they have disabilities, are racially or ethnically different from us, are from language-minority groups, or are just plain poor -- this focus cultivates within us a self-centeredness that impairs us from focusing on care and responsibility for others.

Does it not therefore surprise us that "claimant politics" (id. p. 61) and "interest group" politics have played their roles in shrinking the pool of federal and state funds available for people with developmental disabilities (Braddock, 1990). (See recommendation 1.)

Is it any wonder that research, training, and demonstration funds in the field of developmental disabilities are far more constrained than at any other time in our nation's history (Braddock, 1990). (See recommendation 12.)

Is it any wonder that concerns for cost-containment and managerial efficiency corrupted the Social Security benefit system and caused a Supreme Court decision that lambasted the Social Security Administration for its mean spiritedness and callous disregard of the statutes (Sullivan v. Zebley, 1990)?

Saul Bellow has a trenchant observation to make about the consequences of our pursuit of liberty. He (quoted in id., p. 57) notes, "Nobody truly occupies a station in life any more. There are displaced persons everywhere."

Let us consider how there are displaced persons, looking through the prism of developmental disabilities.

Is it any wonder that resistance to mainstreaming students with disabilities into program for students without disabilities has provoked such resistance? Displacement occurs when people with disabilities can be extruded from the lives of others like them. (See recommendation 6.)

Is it any wonder that the effort to close state institutions has failed and that resistance to group homes is commonplace? Displacement occurs when neighborliness does not mean living near or next to someone unlike ourselves. (See recommendation 1.)

Victor Havel, a poet before he became the president of Czechoslovakia, has observed that "consciousness precedes action." What is our consciousness?

Do we not still believe (as Vince Lombardi said) that winning is not everything, it is the only thing? Do we really disagree with Thomas Hobbes, who noted, (quoted id. p. 83) "there is no other goal, no other garland, than being foremost"?

I suspect that each of us knows a person who has experienced a relatively new middle-class worry, one that Bellah and his colleagues have identified. It is that, as the middle class lost ground in the race to keep up with the rich and the poor became even poorer, its members have become more and more aware of the fragility of their own affluence (id. p. 88) and less and less willing to identify with the plight of the less well off and with social justice causes (id. p. 88). This worry is salient to individuals with disabilities, though Bellah et al. do not address them. Thus, instead of trying to "level the playing fields" so that people with disabilities can take advantage of economic opportunities, some people have resisted affirmative action programs that result in people with disabilities being given a leg up.

That is one reason why policy makers and their constituents view "supported employment" as a short term entitlement (limited to 18 months) that benefits only the worker with a disability. They are too close to their own fragility to think of it as benefiting the workplace and coworkers alike, as a program that is indeed for everyone, not just the person with a disability. Unfortunately, that very sense of vulnerability is a powerful motivation for

workers in state institutions, sheltered workshops, and special education: thinking their jobs threatened by deinstitutionalization, defacilitation, or desegregation of special education, they resist that which is programmatically efficacious, economically sound, legally compelled, and morally right. (See recommendation 4.)

Beneath this resistance to economic legs up and other real-life opportunities for people with disabilities lies our failure to come to grips with the reality that we are all interdependent, disabled upon nondisabled, nondisabled upon disabled, and nondisabled upon nondisabled. The fact is that in our work as elsewhere we rely on each other. We are truly "job coaches" and "supported coworkers" to each other. We do "job sharing" with each other. But we still resist that interdependency when faced with employing a person with a disability and a job coach or making reasonable modifications of the workplace, modifications that benefit us all. (See recommendation 4.)

On a more fundamental level, we have not yet agreed that every American, disabled or not, should have as a matter of right access to decent health care and a "sufficiency," that is, a secure income sufficient in amount to allow us to "form attachments, make commitments, and engage in activities that are good in and of themselves," even though they do not produce any income (id. p. 105). (See recommendation 5.)

Bellah and his colleagues invite us to look beyond political economics to see that the rugged pursuit of individual interest has ceased to profit us and in many ways has impaired us, whether or not we have disabilities. Bellah et al. do not address the issue of disabilities, but I again want to make their argument relevant to our interests here.

Our belief in the sacredness, uniqueness, and pricelessness of each life (id. p. 114) reflects the value we place on individuals. For many people,

this perspective justifies the "sanctity of life" approach that requires treatment of every newborn with any disability that might possibly be repaired or ameliorated. At the same time, our adherence to "individualistic utilitarianism", the belief that the greatest good is the sum of all individuals' pursuit of self-interest, justifies an ethic that places costs and benefits on lives. This ethic says that an individual's quality of life (measured as the sum of the contributions of the home and society times the individual' natural endowment) is calculatable and that, when costs exceed benefits, the individual no longer may expect governmental protection from medical nontreatment. This is an inevitable result of a cost:benefit criterion for analyzing policy.

This same kind of "neutral" criterion -- a cost:benefit ratio -- also can be used to justify other interventions, such as segregated schools and classrooms, state residential institutions, and the rationing of health benefits. As many of you know, however, it precludes any considerations of empathy, any human understandings and values that are not able to be priced, and the intangibles, such as loyalty, that bind society together (id. p. 123).

Another phenomenon of our country is the appeal to law and the conversion of claims and interests into rights. There are, of course, certain negative rights -- rights of due process and equal protection and rights to least drastic or restrictive alternatives -- that inhibit the government and limit its actions. Thus, a person with a disability may not be adjudicated incompetent, institutionalized, retained in an institution, sterilized, denied an appropriate education, segregated in schools or other settings, subjected to restrictive zoning laws, medicated, put into a behavior modification program, or denied basic and humane care when in state custody, unless there is powerful state interest in doing so. The rights of due process, equal

protection, and least drastic alternatives protect against those kinds of state action.

But the "rights" issue today is more than a matter of asserting negative rights. It is also a matter of converting claims into positive rights. It seeks to convince courts that the constitution means that a person has a right to certain kinds of services. This is difficult to do. The Supreme Court has made it clear that unless a person is in state custody, the person has no claim to services as a matter of constitutional law (DeShaney, Youngberg). It means persuading legislatures that interests are worthy of protection and that entitlements should flow from the recognition of those interests. This too is difficult to do. Although people with disabilities have had some success in creating new entitlements, such as supported employment and assistive technology, the shrinking discretionary funds of the federal government, coupled with slow economic growth, have made this route a painful and not terribly successful one. (See recommendations 3 and 9.)

These claims, when they are converted into entitlements, are called the "New Property" (Reich, cited id. at p. 125). They reflect Americans' expectations of "total justice" (Friedman, cited id. at p. 126) -- an expectation that individuals have a right to permanent security and certainty and that, to secure this result, state and federal governments should be the funders, guarantors, and underwriters of that expectation. In the field of disabilities, the "new property" consists not just of supported employment but also of Social Security benefits, such as SSI, SSDI, and regular retirement and survivors' benefits; of permanency in group homes and sheltered workshops; and even of permanency in institutional settings or nursing homes.

By converting interests and claims into "rights," however, Americans run some risks. First, they acknowledge that, in wanting the individual to be

served, individual claims are more important than other claims. Thus, individuals' rights to liberty may result in their being deinstitutionalized and dumped into an hostile community, just as those very same rights to liberty may prevent their being institutionalized unwarrantedly. In both instances, however, the law's focus has been on the rights of the individual; the community's interests in caring for vulnerable individuals and in their not living as beggars on the streets may be ignored, just as the community's interests in having them detained when they are dangerous to others may be ignored. Similarly, the rights of an individual not to be sterilized may result in the least restrictive reproductive environment for the individual, but it may also result in a single-sex environment and in restriction for the individuals' families (Grady). By the same token, an individual's right to be free from unconsented to medical procedures may protect against that person serving as a vehicle for organ transplant to another (Strunk), but it also may result in that person being unable to donate to and benefit others on whom the person ultimately may come to depend (Strunk). Likewise, a person's right to refuse medical treatment, even if the refusal means a faster death, may preserve that person's rights and the rights of others like her, but it also may mean that the person's family loses all control and rights over its family member (Cruzan). As many critics have noted (Minnow, Glendon, Bellah et al.), an inevitable result of creating or honoring rights is to create conflict between rights claimants. That conflict can deflect us from attending to the common ground that the claimants may occupy; it may divert us from debating the common good because we focus on the individual good (id. p. 128-9). When all rights are equal, no rights are more worthy than others, and no rights "trump" other rights.

Of course, we have been able to create "escape hatches" and "safety

valves" when rights conflict. The parent who does not want to take the "defective newborn" home from the hospital need not thereby condemn the child to die; adoption and foster care, and even institutionalization, remain as options. Likewise, when a parent refuses life saving treatment for a child with Down syndrome, parental rights may be transferred to others (Becker). Similarly, a parent who cannot keep a child at home, even after specialized help is provided (as by family support and by family reunification efforts), still has an option to abandoning the child; institutionalization is one option (Parham), and so is foster care and adoption. (See recommendation 3.)

By and large, however, a focus only on rights can polarize and prevent dialogue on the nature of the common good. It can pay too much attention to the individual, to a "win or lose" or "zero sum" result, rather than to a community, "win-win" result. Basically, it ignores a very fundamental and very old axiom: each person's liberty is a result of each other's person's agreement to surrender some liberty; each of us must surrender some liberty in order to have any liberty. As social beings of necessity, not choice (Hobbes), that is so; as members of a highly interdependent society, where economic, political, and legal interdependency, not independency, are the norm, that is especially so.

Yet it remains true that the community interest is submerged in the rights debate, even the "community" that exists within the family (Minnow). To quote Bellah and his colleagues, the "individualistic language of rights at the heart of the American legal tradition is a way of talking about the common good that inadequately addresses the kind of interdependence that is crucial in modern society" (Bellah, id. at p. 130).

IMPLICATIONS OF A COMMUNITARIAN FOCUS FOR DISABILITY POLICY

Let me now tie these observations to the future of people with developmental disabilities and to the roles that developmental disabilities planning councils and state governments may play.

Remember: my argument is not against the "individual autonomy/liberty" precepts of our constitution, economy, and legal system. I certainly do NOT suggest for a moment that we should even think about jettisoning some of the hard-won rights of individuals with disabilities. Far from it. To put these rights at risk is to invite a return to the past, when the absence of rights caused consequences that I reviewed for you earlier (Table 1).

Nor do I suggest that we abjure our concerns with equality of opportunity and the formulation of concepts of equality that allow for compensatory or transitory justice and, that recognize that special adjustments must be made for people with disabilities so they may be treated equally in terms of their opportunities. The bold efforts of the IDEA and ADA to create a more equal world -- to ameliorate the condition in the individual and to adjust the world of the individual by requiring the rest of us to accommodate -- should be pushed even farther, particularly in the immediate post-ADA days.

My argument instead is in favor of a different balance between the competing values of liberty, equality, and community. I suggest, cautiously, that we will have a richer and more satisfying future if we focus less on "liberty" and "autonomy" of individuals and more on "community" and "the common good" of all of us (Turnbull, H. R., and Brunk, G., 1991).

I take my cue from Bellah and his colleagues. In Habits of the Heart, Bellah and his colleagues argue that the individualistic traditions in America have made it difficult for Americans to "sustain their commitments to others" and have caused many of us to feel that we are isolated from our families,

friends, neighbors, community institutions, political parties, and elected and appointed officials. They point out that we often think of ourselves as being pitted against institutions and as not needing each other or institutions to enrich and sustain our lives. They draw a sharp distinction between "philosophical liberals" and "individualistic utilitarianism" on the one hand and "communitarians" and "civic republicanism" on the other.

The former -- the individualistic and liberal perspective -- seeks individual self-fulfillment by structures of the economy and government that maximize individual freedom. Thus, government's role is to maximize individual preferences by ensuring a free market economy and a legal structure that inhibits to least possible degree the individual's freedom to maximize his/her preferences.

By contrast, the communitarians and community-referenced political philosophy holds that <u>there is no individual freedom without group and community participation</u>. "We hold up other traditions, biblical and civic republican, that had a better grasp on the truth that the individual is realized only in and through community...." (id. at p. 5).

In their second book, <u>The Good Society</u>, Bellah and his colleagues argue that institutions such as local, state, and federal government, voluntary associations, corporations and other business entities, schools and universities, and churches and synagogues, "afford us the necessary context within which we become individuals" and that institutions are "not just restraining" but are "enabling" and an "indispensable source from which character is formed" (id. p. 6). Contrary to the individualistic perception that freedom consists primarily of autonomy and self-fulfillment, of self-reliance and independence, "we are not self-created atoms manipulating or being manipulated by objective institutions. We form institutions and they

form us" in our roles as colleague and friends, teachers and students, parents and children, elected officials and voting citizens, and so on. Institutions such as the workplace (corporations and other business entities), schools and institutions of higher education, families, government, and even churches and synagogues "are the substantial forms through which we understand our own identity and the identity of others as we seek cooperatively to achieve a decent society" (id. p. 12). Bellah and his colleagues do not argue that Americans should dispense with institutions, although they say that institutions are part of the reason we feel powerless. Instead, they argue that "only greater citizen participation in the large structures of the economy and the state will enable us to surmount the deepening problems of contemporary social life" (id. at p. 6).

Bellah et al. argue, the classical liberal view has elevated one virtue, autonomy, as almost the only good, but has failed to recognize that even autonomy depends on a particular kind of institutional structure and is not an escape from institutions altogether" (id. p. 12). Moreover, the very principle of autonomy, as it has been played out in our market economy, policy making, laws, and government, has put more emphasis on self-aggrandizement and less on "responsibility and care, which can be exercised only through institutions" such as the family, schools, business entities, and government.

Although I have taken my cue from Bellah et al., I acknowledge as well the influences of the work by Glendon (Rights Talk) and Minnow (Making All the Difference). As I noted earlier in this paper, their argument is that the rights-focus has obscured a responsibility-focus, that an individualisitic ethic has overshadowed a community ethic, and that the consequences have been and will continue to be unwelcome and unproductive.

Not unexpectedly, there are others who have been concerned for a relatively long time with the issues of community and responsibility; the Bellah, Glendon, and Minnow writings are more contemporaneous but not by any means the only voices of concern. A new journal, The Responsive Community, published first in 1991, is subtitled "Rights and Responsibilities." Among its editors are Mary Ann Glendon and Amitai Etzioni, whose recent essay in that journal argues that communities embrace moral standards and teach those standards, acting like "moral colleges"; the moral standards must be nondiscriminatory (applicable to all members of the community), generalizable (justified in terms available to all members, not just some); and broadly based (reflect the basic human needs of all of its members). "In short, communities are to be valued by the extent to which they are responsive to their members, and the proportion of all the individuals that there are which they can encompass in their responsiveness" (id., p. 8).

Ethicists also are coming to grips with the nature of modern America and the policies that should guide us in "hard times" -- namely, when the post-modern economies are less than abundant. Daniel Callahan has been particularly persuasive about "ethics in hard times." In a book of the same title, he addresses the conflict between individualism and autonomy and the "hard times" that have today gripped our national and international economy.

> "Hard times require self-sacrifice and altruism -- but there is nothing in an ethic of moral autonomy to sustain or nourish those values. Hard times necessitate a sense of community and the common good -- but the punitive virtues of autonomy are primarily directed toward the cultivation of independent selfhood. Hard times demand

> restraint in the blaming of others for misfortune -- but moral autonomy as an ideal makes more people blameworthy for the harms they supposedly do others. Hard times need a broad sense of duty toward others, especially those out of sight -- but an ethic of autonomy stresses responsibility only for one's freely chosen, consenting-adult relationships." (Callahan, 1981, p. 19).

It should not be surprising to recall that some of the major social planners of our times themselves have been "communitarians". Titmuss views social policy as concerned with reciprocal obligations and the maintenance of social and community relations (Titmuss, R., 1968 and 1971). Boulding (1967) has argued that the goal of social policy is to "build the identify of a person around some community with which he is associated." Moroney (1981) provides us with examples of other "communitarians" among contemporary social planners, welfare specialists, sociologists, and social scientists.

My point in citing to the ethicists and social scientists is to note, quite simply, that there is indeed a powerful, albeit minority, strand in our nation's fabric, a strand that calls us nowadays toward rebalancing rights with responsibilities, refocusing on the needs of all instead of just the needs of one of us, and reexamining contemporary policy in lights of the past and likely future in an increasingly interdependent world. Thus, although I have taken my cue (for this paper and another, Turnbull, H. R. and Brunk, G., 1991) from Bellah and his colleagues, it is not on them alone that I have relied for my arguments in favor of the communitarian perspective in disability policy.

TABLE 2

PERSPECTIVES ON VALUES

Liberty, autonomy, self-determination: the "libertarian" approach

Equality, especially in opportunity: the "equal protection" approach

Community, especially interpersonal: the "communitarian" approach

Now, let me make Bellah et al.'s observations relevant to the field of developmental disabilities, by asking you some questions. Why are we now seemingly so unhappy with the way the field has developed; why do individuals with disabilities and their families say that major problems are loneliness, isolation, disconnection, and powerlessness? Is it because they have begun to realize that our vision of the atomistic and autonomous individual, our adherence principally to individualistic utilitarianism, and the consequnces of this vision and allegiance, have become insufficient for our lives -- necessary, but not sufficient, and arguably overvalued in a world that is increasingly interdependent? Bellah and his colleagues think so, without reference to the disability field, and I think so in connection with the disability field.

What else explains the return of "power to the people" in such forms as "family empowerment" and "self-advocacy movements" in the disability field? (See recommendations 3 and 8.)

Why else have we become so uncomfortable with the technical approach to our problems, an approach that says, for example, that a cost:benefit analysis is proper to determine which newborn with a disability will receive certain treatment or nontreatment.

Why else have we become suspicious of a science (behaviorism) that says that every human behavior is learned and can be corrected by any technical means at our disposal, including aversive interventions? (See recommendation 12.)

Why else are we distressed when we confront the argument that a decision on the amount of support that an individual with a disability needs and should have on a job or in a school is a function of a trade-off between the costs of the accommodation and the benefits to the individual and society? (See recommendation 12.)

Why else do our regulatory agencies look askance at such "intentional communities" as the Camphill communities and L'Arche group homes, which are largely unregulated by government and receive "quality assurances" not from regulatory agencies but from an animating spirit of mutual commitment to the community and of each member to each other? (See recommendation 7.)

Why else are we beginning to pay attention to the role of "informal support" in school (e.g., peer tutoring, best buddies, etc.) and on the job and seek to merge informal support (given by families and friends) with the "formal support" provided by traditional governmental agencies? (See recommendations 4 and 6.)

Why else, having bought into the competitive race that measures progress by our attaining certain SAT/ACT scores and admissions to selective universities and colleges and by our acquiring certain advanced degrees and status symbols, are we adamant that minimum competency testing of individuals with disabilities may discriminate against them or result in their learning the "wrong" skills? (See recommendation 6.)

Does the disintegration of our nuclear family structures explain why we are now so keen on "family support" policies and programs, where families

direct the use of state resources rather than being told what is available, what they need, and what they will receive? (See recommendation 3.)

Are we upset by the Cruzan decision, upholding a high standard of proof before a family may order their disabled child disconnected from life-saving medical treatments, because we sense that on the whole a family is a better decision-maker than the state, at least when the family is unanimous in its opinions -- that the family exhibits more care, concern, compassion, and responsibility towards its own members than does a state whose laws are founded, explicitly and directly, on an anti-abortion premise? (See recommendation 3.)

Have we begun to form political coalitions (with the AIDS and SOS/aging interest groups) because it is merely politically expedient, or because we in the disability field recognize that a common interest exists in creating programs of long-term care for long-term needy people? (See recommendation 1.)

Have we begun to understand the deeply philosophical implications of the change of our language -- from "the disabled" to "people first" terms, from a concept of "independence" to "interdependence," from "productivity" to "contributions", from "integration" to "inclusion"; that these changes in terminology are ways of saying that there is something more to life than competing, that in fact cooperating, being "of" not just "in" the community, is itself a greater good? (See recommendations 1, 4, and 6.)

Have we begun to justify integration and inclusion in schools and residential neighborhoods not only on the ground that segregation is wrong but also on the ground that integration and inclusion themselves have values to people without disabilities, allowing them to display their concern, responsibility, and care for others, and to people with disabilities, allowing

them to enrich the lives of other people? (See recommendation 6.)

Are we now focusing on ethics in the field of disabilities because we have learned that technology alone is not enough, that a reductionistic, mechanistic, empiricist, and relativistic view of people (ourselves and those with disabilities) does not capture the full range of human understanding and possibility? (See recommendation 12.)

Are we now beginning to acknowledge that there are too many rights, with no rights that are superior to others (no "trumps"), and too few obligations that are not rights-based (Minnow, Glendon, Bellah et al.), and that, however reluctant we are to surrender our hard-won rights and however determined we are to advance them, we have begun to think about moving "beyond rights"? Have we begun to recognize that the ultimate failure of the "rights" perspective is that it preserves an individual benefit for the winner, and an individual loss for the loser, without allowing them both, and all of us together, to consider and evaluate how we can achieve the common good (Bellah, id. at p. 128-9)? (See recommendation 1.)

Do we express our disenchantment and disillusion with politics by not voting, by disengaging from the process, by keeping silence except on issues that directly affect us? Do we vote only our pocketbook interest and lose confidence in government and the political process when it fails to satisfy that interest? Do we see the political process as more concerned with interest group good than the common good? (See recommendations 1 and 7.)

Is that why state developmental disabilities planning councils and other disability entities, such as parent information and training centers, are preparing family members and individuals with disabilities to be "partners in policy" -- because they too want to have their pocketbook interest counted? Because we are concerned with maximizing our preferences in a competitive

arena (id. at pp. 131-3)? (See recommendation 1.)

Are we fascinated with the "Japanese model" for corporate governance and productivity simply because it seems to produce more and better goods more efficiently and less costly, or because it reflects a real role for workers in business decision-making? (id. at pp. 94-102). Or is it because we have finally come to realize that "the work each of does is something we do together and for each other as much as by and for ourselves" (id. at p. 105), and therefore the concept of "supported work" is really just a disability phrase that applies to each of us as we work with each other, whether or not any of us have disabilities? (See recommendation 4.)

Have we begun to think about our economic status as so imperiled by corporate takeovers, RIFs, world economic developments, the weather, burnout/blackouts, "viruses" and "bugs" in our computer programs, or other forces beyond our control that we have begun to think about a "sufficiency" (a secure, modest income for all Americans, allowing each of us, not just those who have disabilities, to have a different kind of life, one in which predictability and the concomitant ability to make commitments is the goal)? (See recommendation 5.)

Have we begun to agree with Christopher Jencks that the role of economic policy, for ourselves and those with disabilities, must be to reduce the "punishment of failure and the rewards of success" (Jencks, quoted in Bellah et. al., 1991, at p. 106)? (See recommendation 5.)

Have we belatedly in the disability field begun to think about the role of choices, consent, preferences, and self-determination because we ourselves know how important it is to our own self-fulfillment and self-esteem to be able to chose what we do, or is it only because we know that increased choice causes more appropriate behaviors? (See recommendation 8.)

Are we in favor of mainstreaming, least restrictive educational placements, the regular education initiative, the supportive school concept, the full inclusion idea because they solely are ways better to educate people with disabilities, or because they remind us that, in John Dewey's terms, the school "introduces and trains each child of society into membership within such a little community, saturating him with the spirit of service, and providing him with the instruments of effective self-direction (that) we (then) shall have the deepest and best guaranty of a larger society which is worthy, lovely and harmonious" (Dewey, quoted id. at p. 152)? (See recommendation 6.)

Do we desire the institutions of higher education to be open to individuals with disabilities because then, and only then, will each nondisabled student have to confront the issues of difference and diversity, so that, by so confronting them and entering into a face to face relationship and intellectual discourse about diversity, each will become a "voting citizen of (the) world, rather than a bound vassal to an inherited ontology" (Ohmann, quoted id. at p. 171)? (See recommendation 6.)

I would hope that your answers would be "yes" to all of these not-so-rhetorical questions. I would hope that you would agree with the premise that Bellah and his colleagues have set forth in Habits of the Heart and The Good Society. Let me revisit that premise and then make suggestions that a state developmental disabilities council may consider if it wants to act on that premise.

Bellah and his colleagues adopt a quotation from Dennis McCann as their touchstone: "the common good is the pursuit of the good in common" (id. at p. 9). For them, the pursuit of the common good means readjusting our thinking so that we pay less attention to our own individual needs and more attention

to the needs of the entire body politic; democracy, as they say, means paying attention (id. at pp. 255-286).

It also means acknowledging the very interdependency we have with each other and seeing it as a means for the good life: "Developing the capacity to cultivate a shared form of life may make the difference between a personal life rich in connection and meaning and one bereft of lasting satisfaction. Opportunities for taking a responsible part in a shared life sustain the life not only of families but of schools, communities, religious organizations, business enterprises, nations, and even, as we are now coming to see, a habitable planetary exosphere" (id. at p. 93).

The common good, they argue, "is clearly not the same as the sum of individual goods" (id. at p. 97). This is so because of the interdependence of our lives:

> "The interdependence of modern society is particularly problematic for Americans. A political tradition that enshrines individual liberty as its highest ideal leaves us ill prepare to think about ways of managing a modern economy or developing broad social policies to meet the needs of society as a whole. Yet it is more and more difficult to avoid a consciousness of 'society as a whole' -- and, indeed, of the world as a whole" (id. at p. 113).

If so, what is the task you face? I think that it is, to detach yourselves from self-interest and "persuade a democratic society to take its own injustice seriously," in Ronald Dworkin's words (quoted id. at p. 141).

SUGGESTIONS FOR COUNCIL ACTION

In your roles as policymakers in the field of developmental disabilities, you have the opportunity to address the issues of interdependency, of "society

as a whole".

If you are of a mind to do so, here are some concrete steps you might take, focusing not just on individuals with developmental disabilities but on nondisabled people as well -- on your state as a whole. I have organized these suggestions into thirteen different categories and previously have referred to many of these recommendations. You may be aware that the National Conference of State Legislatures (1991) recently has published a book replete with recommendations for state laws and policies. My recommendations may overlap some of those.

The 13 categories are as follows:

1. Generic agencies' roles
2. Informal support
3. Family-focused action
4. Supported employment
5. Financial sustenance
6. Special education
7. Quality assurances
8. Self-advocacy
9. Monitoring and protection and advocacy
10. Governmental structure
11. Courts and judicial administration
12. Research
13. Prevention

1. <u>Generic Agencies' Roles</u>

* consider funding or helping to get funding for nondisability, so-called generic agencies, to accommodate individuals with disabilities

* help generic agencies accommodate individuals with disabilities and

even fund them to do so

* discourage the use of guardianship and encourage the protection and advocacy efforts at local levels, such as by generic and specialized agencies become mini-P&A agencies

* create local and state "parents as policy partners" programs, and involve not just parents/family members who have children/ relatives with disabilities, but also community leaders who may have no interest in disability issues but who have a track record of looking after the common good

* consider organizing or sponsoring a summer institute for family members, their professional service providers, and their members with disabilities on "visions, goals, and action plans: the power of one in every community"

* encourage funding on research and model demonstration programs that seek inclusion, not just integration -- that address deliberately the issue of "association" -- and consider funding them to generic agencies, not disability agencies (such as community arts councils)

* taking a cue from the Highlander Movement, consider sponsoring a week-long retreat for disability and other community leaders, in the mountains of western North Carolina, so that there can be planned effort, and inspiration, for inclusion, contribution, and interdependency

* if you want to be very radical, consider putting no more money into the disability system but all of your money into the nondisability, generic systems, so that they will accommodate, because we know that disability systems can't do inclusion alone and even have disincentives to doing inclusion

* remember that a disincentive to disability programs becoming more inclusive is that they then lose their "clients" (the commodification of individuals with disabilities), and thus you may want to encourage transition from institutions to community, from workshops to real job, not by funding the disability agencies to do that but by funding nondisability agencies to accommodate, using the disability agencies for technical assistance

* consider the choices and needs of people with disabilities (jobs, housing, medical care) and how generic systems can satisfy them (mainstream the problem and the solution)

* encourage the teaching of disability law in the law schools, of "employability of people with disabilities" in the business schools, and of other disability-related topics in other professional schools

2. Informal Support

* encourage the use of "informal support" by coworkers, fellow students, generic agency providers, etc.

* fund a few "community partners" or "circle of friends" grants to demonstrate and evaluate the "informal support" concept and try to have these projects run by generic, not disability, agencies (remember, circles of friends benefit everyone, and the encircled person is not always or even primarily the person with a disability)

* recognizing that loneliness is a major problem for individuals with disabilities and their families, encourage more "community partners/circles of friends" activities, more integration/inclusion activities in schools, etc.

3. Family Focused

* oversee the implementation of Part H of IDEA so that, after early intervention, there are school programs that are family-centered, and oversee the implementation of the state rehabilitation services agency so that it too takes a family-centered perspective when dealing with adults with disabilities

* encourage family preservation efforts by the state child welfare agency and discourage the use of institutions

* examine your state's laws on withdrawing of medical treatment in cases of futility to determine if, as in Missouri, they pose such a high barrier to family decision-making that the family and person/patient are captive of medical technology and the state's parens patriae interest

(note: the Cruzan family was of unanimous mind; if there is conflict, then a far greater role of the courts is warranted)

* create or encourage the creation of Parent to Parent programs in your local communities, as methods for family empowerment

* examine your laws to determine if there is separate "family support" legislation and your state budgets to determine the degree to which family support programs are funded and evaluated

* consider funding or encourage the funding of research on family unification techniques

* consider funding or encouraging the funding of research on reasonable efforts that are family friendly"

* in order to help the human service system become more flexible, consider legislation like family support, which provides vouchers to "consumers"

* consider sponsoring "parents as teachers to professionals" programs, statewide and locally, so that the parents/families and professionals/ providers will have reasons and structures for "role reversals" that will help the parents/families know how to impart their knowledge to professionals and the professionals will learn how to accept and use that knowledge

4. Supported Employment

* encourage supported employment, with particular emphasis on the use of informal supports, in order to increase the contributions, productivity, integration, and inclusion of individuals with disabilities and to keep them as taxpayers, not tax dependents, people able to earn their own subsistence

* place particular emphasis on supported employment by coworkers, so that, if and when the job coach is no longer fundable by the rehabilitation agency, there will be job sharing, transportation pooling, flex-time possibilities, etc. for workers with and without disabilities (remember, supported employment is for everyone, not just the person with a disability)

* encourage disability-provider agencies to employ people with disabilities, as role models, but do not limit the affirmative action effort to just those agencies

5. Financial Sustenance

* examine the state's laws and financial aid streams to determine if they provide a decent and livable sustenance

* in recognition of the fact that federal funding is decreasing while state participation in federal-state programs imposes a greater cost on state and local government budgets, consider that disability programs still have not tapped into generic programs as much as they might (e.g., Carl Perkins Vocational Education Act), and thus consider how to expand

the "disability dollar pool" by leveraging disability funds into and with generic funds (e.g., Medicaid pays for some related services)

* consider how the state's fiscal base might be directed at improving the entitlements of individuals with disabilities, since it is clear that as the federal fiscal base feels constraint the federal entitlement programs will diminish in importance and value and demands on the state fisc will increase (a trickle-down effect)

* because bureaucracy costs, consider how to reduce the administrative components of developmental disability programs so that more funds can be targeted directly to individuals with developmental disabilities (as in "vouchers" and "family support" or "limited/targeted case management" initiatives)

6. Special Education

* directly confront the school reorganization, regular education and supportive school initiatives (all various versions of the LRE issue) and deal directly with the structural barriers in schools to inclusion

* encourage the state education agency to develop an outcome-based accreditation program for special and regular education, and to use it for accreditation/monitoring purposes

* encourage school systems to use community-based, community-referenced curricula, not just for students in transition from school (as required by IDEA 1990 and implied by ADA 1990), but also for younger students (on generalization and maintenance/durability grounds)

7. Quality Assurances

* advocate for a zero-reject, appropriate services law so that providers for adults must comply with the same standards of service delivery as the public schools

* consider advocating for a mandatory AIDS-testing program for individuals who serve those with a developmental disability, and for individuals with a developmental disability, when there is interaction that may transmit HIV-AIDS viruses

* consider AIDS prevention efforts for individuals with developmental disabilities, including sex education/family life training during and after their school years

* recommend the discontinuation of aversive interventions and the adoption of nonaversive interventions for challenging behaviors

* consider sponsoring "getting to yes" meetings of families/advocates and professionals/providers so there can be contingent-free opportunities for joint planning, discussions about system improvements, etc.

* when considering the community based programs and the inevitable and laudatory direction toward supported living, plan for quality assurance in the programs seek the special attention of the state P&A system on quality assurance and rights-abuse issues in community programs, devise

more informal support programs that themselves are forms of quality assurance and communitarian caring, and try to de-specialize/ defacilitate by having generic agencies do more of the community living/supported living activities as a means for "mainstreaming" the issue of supported living and taking advantage of the quality assurances provided by generic systems (with support from the developmental disability system)

8. Self Advocacy

* consider requiring grantees of state funds to ensure self-advocacy components in all of their activities (e.g., boards of directors, boards of advisors, committees, etc.)

* fund and encourage the development of self-advocacy groups at the local level and fund an annual self-advocacy conference at the state level

* encourage local and state agencies to ensure the maximum amount of "consumer" (individuals with disabilities and their families) participation in decision-making, monitoring, etc. (the threshold issue is "grassroots participation")

9. Monitoring

* monitor medical care and develop adoption and foster care options for families who do not think they can care for newborns with disabilities

* examine the state's laws to determine what limitations they place on individuals with disabilities and whether those laws might be repealed or modified or whether the laws applicable to all of us need to modified to accommodate individual with disabilities

* consider funding demonstration programs on "personal cognitive assistance/assistants" so that there will be mini-P&A programs that may avoid guardianship and incompetency proceedings

* encourage the P&A agency to develop and implement system-change strategies, not just individual case advocacy

* consider funding mini-P&A agencies that essentially serve as "information-referral" and "mediation-ombudsman" groups

10. Governmental Structure

* consider, with state and county/municipal authorities, how the decentralization movement of the federal government (via deregulation and other techniques) affects your state and whether decentralization of decision-making and regulation (and perhaps funding) is desirable and, if so, under what circumstances and how the decentralization may affect service-delivery, particularly with regard to quality assurances, monitoring, and rights-enforcement

* be very wary of "privatization," because the private sector has very little accountability, commodifies individuals with disabilities, has discriminated in the past, may not be able to provide appropriate services, and may lack incentives to serve those who have greater needs

(the agencies "cream")

* if privatization is appealing, make sure that there are quality assurance provisions, accountability mechanisms, incentives to serve those with greater needs, low overhead and high direct service expenditures, a high degree of client/consumer participation, and a zero policy and program

11. Courts

* work with the court administration system to implement a plan for access to the courts, as proposed by the National Judicial Conference and the American Bar Association Commission on Mental and Physical Disability Law and the Commission on Legal Problems of the Elderly

* consider whether your criminal justice, police, fire, and emergency medical service systems are adequately trained to deal with individuals with disabilities and, when appropriate, to divert them from criminal justice systems and into more habilitative systems

* seek to have the state Supreme Court adopt and implement the standards for the criminal justice system adopted in the mid-1980s by the ABA upon recommendation of the ABA Commission on Mental and Physical Disability Law

* if the state has the death penalty, examine whether it is being applied to people with mental retardation and determine whether an exemption from capital punishment for them is possible (it is desirable)

12. Research

* encourage funding of research on the biobehavioral states of persons with profound disabilities

* ensure that there is "participatory action research" or "participatory research" in the state-funded research and demonstration projects

13. Prevention

* if you deal in the area of prevention, remember that much prevention occurs not by discovering cures to biological anomalies, but by eliminating lead-based substances, providing better maternal health care (pre-/peri-/post natal), and providing early intervention for at-risk children (these are issues that the disability community perhaps can stimulate among public health agencies, but they certainly are issues that will divert or exhaust the resources of the developmental disability system if that system itself addresses them alone)

* engage in a serious debate with all affected parties concerning the prevention of fetal-alcohol, "crack-affected", and HIV-affected children, remembering that any discussion of those issues carries heavy socio-economic-racial overtones

* if you chose to focus on the "high risk" children and families, do so via the nondisability agencies such as Head Start, public health, and day-care, remembering that there are model interventions

CONCLUSION

Now for some concluding remarks. Let me restate my earlier disclaimer. I am not interested in repealing rights and rolling back the rights revolution. Some of you may know that I have been very interested in rights and the liberty/individualistic issues; certainly my work in North Carolina attested to that. You may recall or know that I was the principal architect of the Creech Bill, creating a state-law right to special education (1977-8), and principal architect of the limited guardianship law (1978-79). I also was the law member of human rights committees at two of the state facilities, an educator of professionals, a co-founder of the first group homes in my county and of the sheltered workshop there, and an activist. But I am today more concerned about community than rights. In all, a balance is necessary between community and rights. So here are some final comments about the role of government and community.

There is a great deal of talk these days about new techniques for service delivery -- about targeted case management and consumer participation in disability service delivery decisions, about community living and quality assurances, about family support and individual self-advocacy and empowerment, and about integration and inclusion, independence and interdependence, and productivity and contribution. In all of this talk, let us remember that what we need most is the common good, and that the common good arises from pursuing that which is good in common (as Bellah et al. remind us, id. p. 9). What is good in common and the common good must be that which makes people with and without disabilities even more aware of their interdependence, that compels a confrontation and dialogue about common dreams and visions, and that does so in ways that helps to ensure a "win-win" result for all.

A very wise friend, Helen Zipperlin, who lives in an intentional community (Camp Hill, in Pennsylvania) gave me insights that I want to pass along to you.

She said that, for interdependence to come to pass, the community needs to know of, acknowledge, and advance the dreams of its members with disabilities and their families. So, your role might best be served by helping to set the stage for communities to come together. The suggestions about generic agencies, informal support, family-focused efforts, supported employment, special education, and governmental structure are particularly relevant to setting the stage.

She also said that no human service system can get a person out of the system unless there is a responsive community. Your role is to help create that responsive community. I refer to my suggestions for ideas how you might do that.

Next, she said this: The challenge is not for government to be so different than it is today. The real challenge is to the community to be different.

She added that a developmental disabilities council needs to help the community "wake up," one person at a time, one generic agency at a time, one church at a time, one school at a time, and so on.

My argument to you is that the "waking up" is to the interdependence that we all have, to the fact that we have had too much individualism and too little community, and to the fact that, for the next ten years at least, the role of government is to help create community.

That is hard, but I hope I have given you some reasons why you should try and some suggestions of how you can act, if you want to try.

As you consider my argument, reasons, and suggestions, remember what my

son, Jay, who has multiple developmental disabilities, has taught his family and friends. It is this:

* the best social security is family and friendship

* family and friendship result only when there is inclusion, only when there are deliberate efforts to "build community"

Thank you for asking me to return to work with you. I hope you take the communitarian direction. Since I left North Carolina 11 years ago, that direction has become more and more important to me as a family member, lawyer, researcher, program developer, and citizen. I suggest that it will become more and more important to us all. Again, my thanks.

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